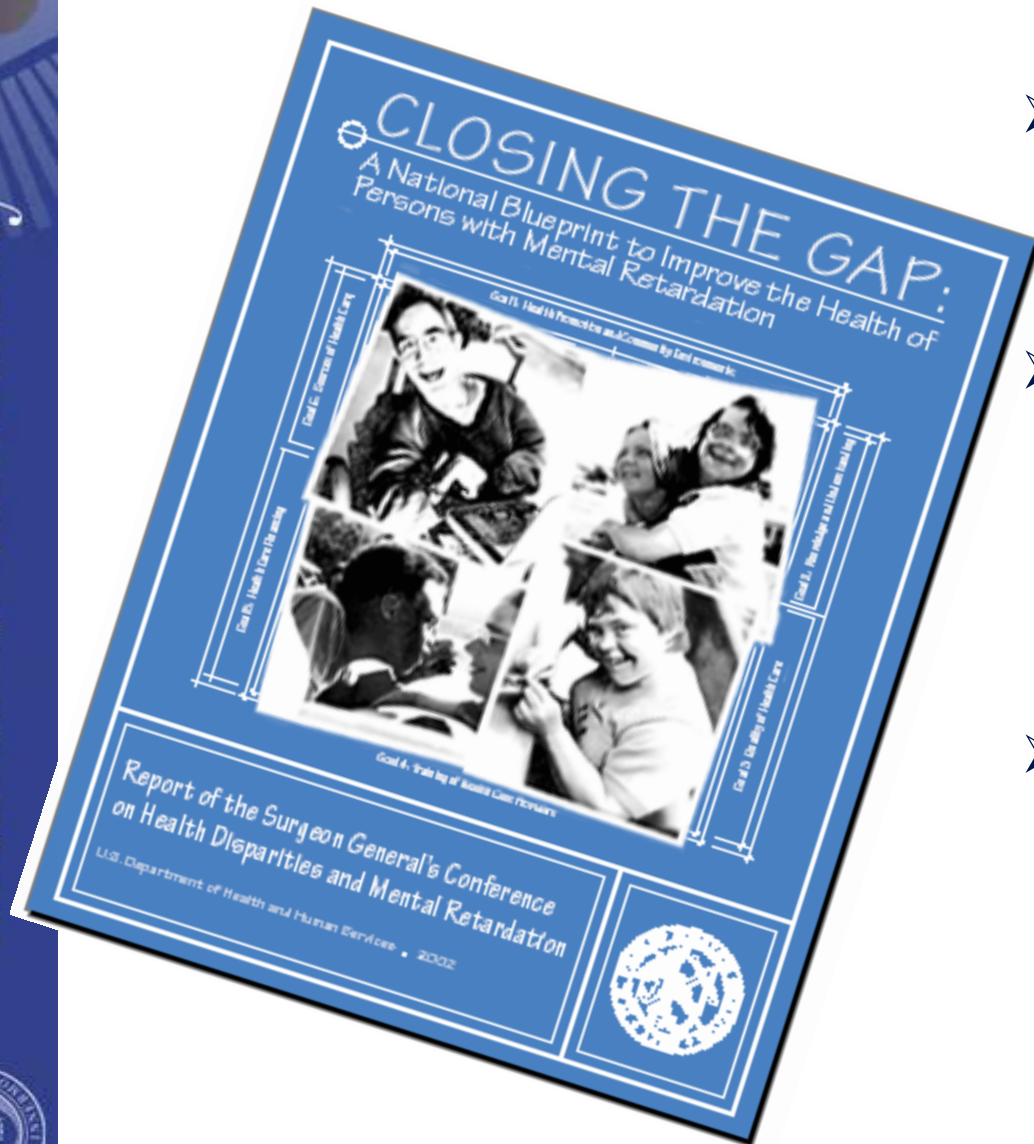


Preventive Health Care for Women with Developmental Disabilities

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Context



- “Cascade of disparities” for people with developmental disabilities (Krahn *et al.*)
- Emerging evidence: Health promotion for people with disabilities is critical yet often ignored (Rimmer *et al.*)
- Established commitments to self-determination for people with disabilities
 - little evidence of implementation in health care

Background: Cervical & Breast Cancer Screening

- Cancer screening recommendations set by the US Preventive Health Services Task Force
- Cervical cancer, once the leading cause of cancer deaths among women, is now completely treatable and preventable with Papanicolaou smear test (Pap test)
- Breast cancer: 2nd most frequently diagnosed cancer & 2nd leading cause of cancer deaths in women
- Routine mammography reduces mortality by ~20%
- Changing guidelines
 - Mammography guidelines changed in 2009 (controversial)
 - Pap test guidelines changed ~3 weeks ago

Background: Cervical & Breast Cancer Screening for U.S. Women with DD

- Existing research suggests women with developmental disabilities have among the worst rates of cervical and breast cancer screening in the United States
 - Limitations: Self-reported or proxy-reported data
- Barriers to care
 - Women's limited knowledge
 - Fear surrounding procedures
 - Physicians' pejorative attitudes
- No evidence-based interventions have been established as effective in increasing women's receipt of screening
- Our focus: Empowering women to be informed, assertive patients

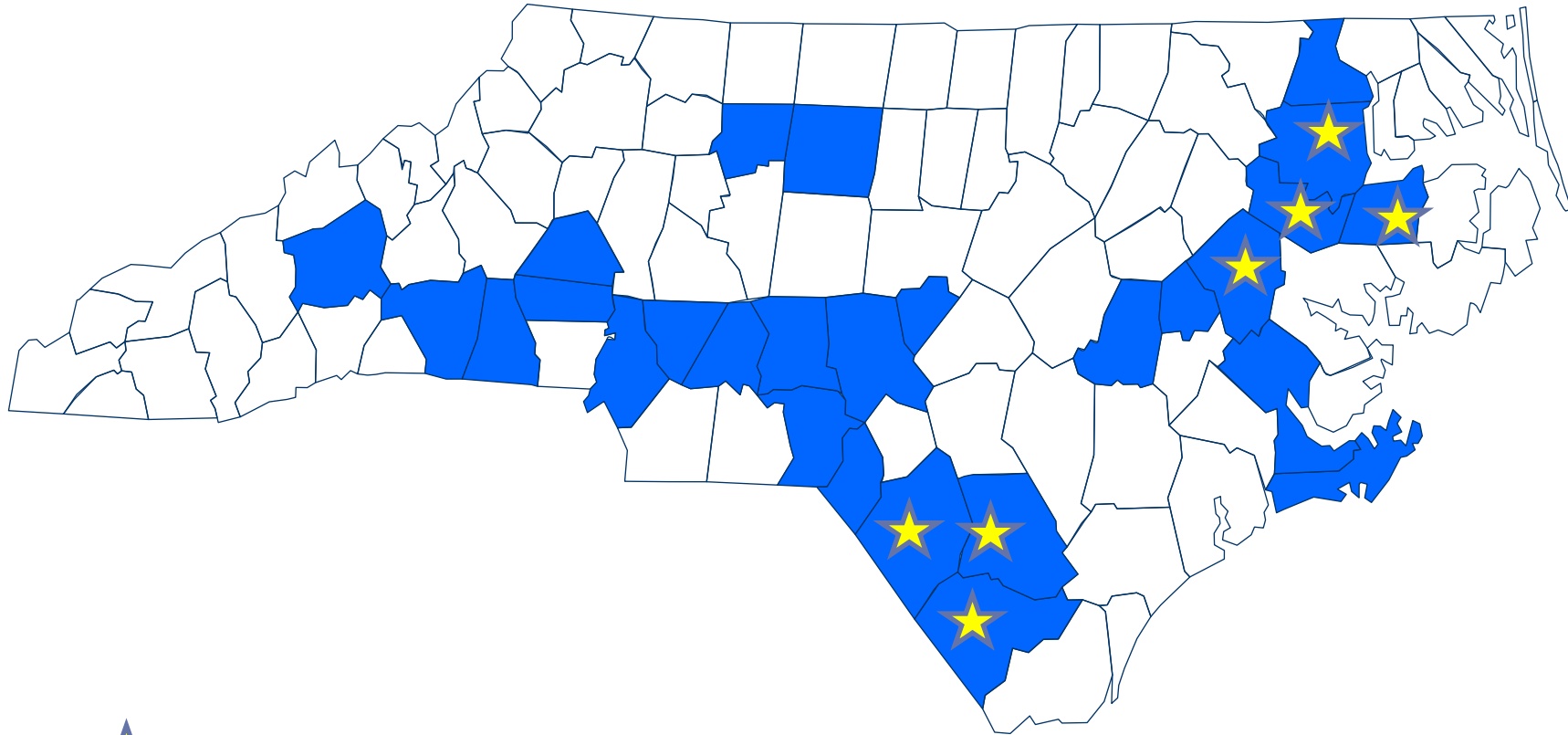
Background: *Women Be Healthy*

- Health promotion intervention designed to empower women with developmental disabilities to obtain cervical and breast cancer screening
- 90-minute psycho-educational classes, once/weekly
 - Eighth week is graduation (7 weeks of instruction)
- Content: anatomy, cancer, importance of screenings, communicating with health care providers, field trip to GYN office
- Preliminary testing: women reported satisfaction
- Developers: Lunsky, Straiko, Armstrong; (revised by Havercamp, Dickens)

NIDRR Field-Initiated Research: Study & Sub-Studies



Participants' counties of residence



★ = Persistently poor counties (>20% of county with income below the federal poverty level for >30 years); 10 North Carolina counties are persistently poor

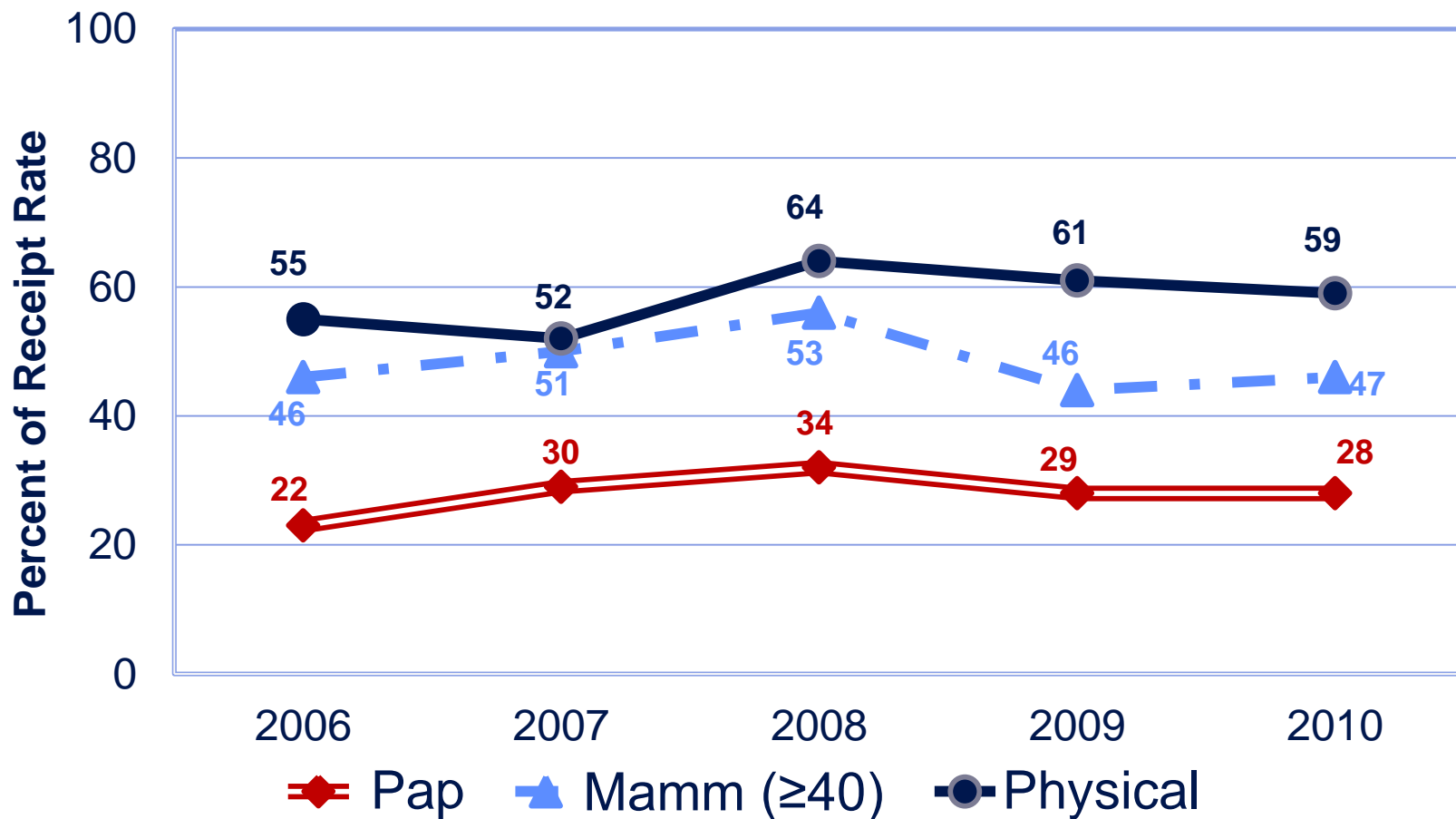
Description of the Sample

Characteristic	n = 203 women
Race is Black	47%
Race is Asian, Native or Latina	3%
Has a child	13%
Lives alone or with partner	8%
Lives in formal residential setting	40%
Lives with family caregiver	45%
Age (mean)	40 years (19 - 71 years range)
Impairment is mild or moderate	91%
Lives in rural area	75%
Insured	>99%

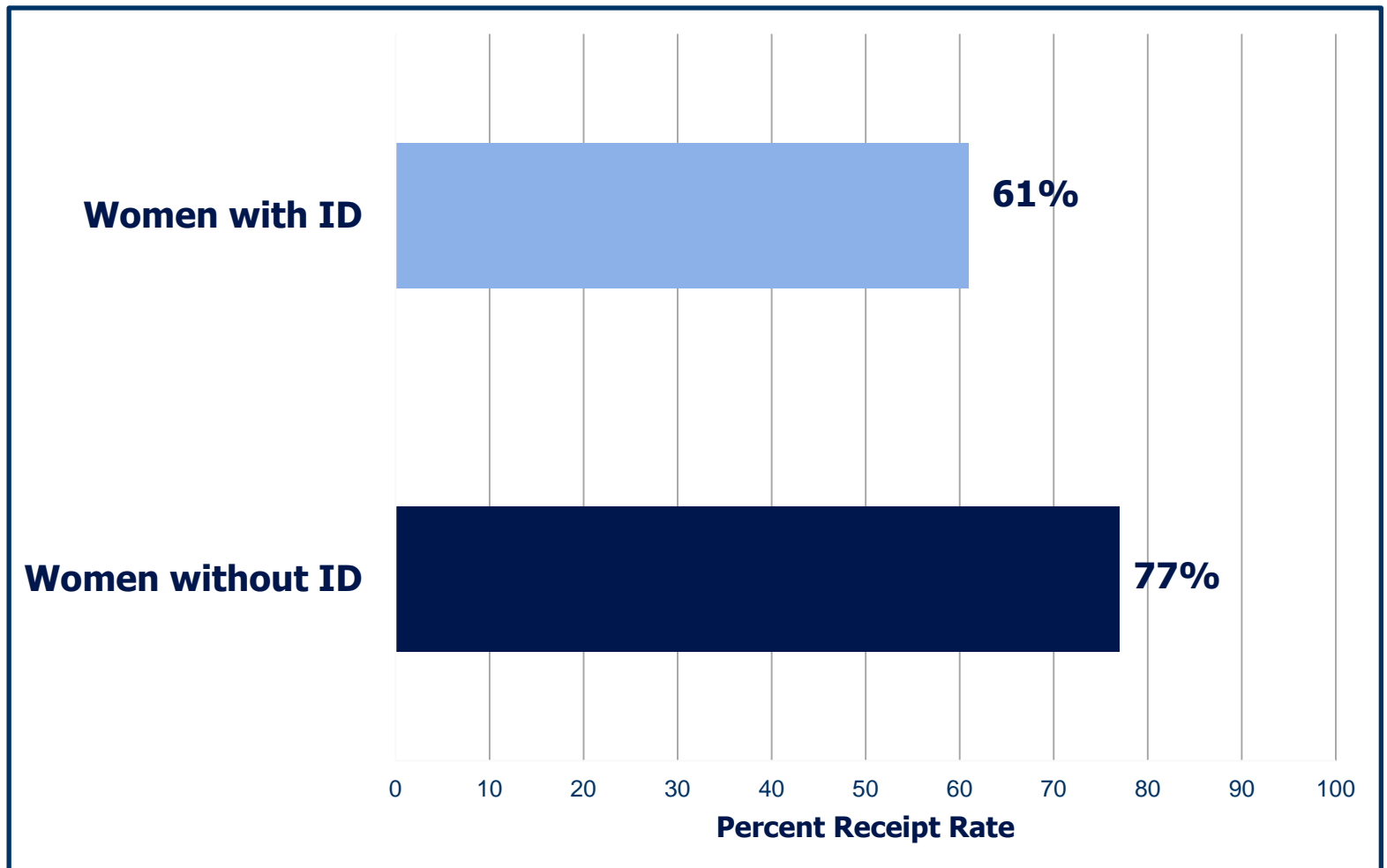
Goal: Determine Cervical & Breast Cancer Screening Rates

- Existing estimates of screening rates derived from self-reported or proxy-reported interview data
 - Biased reporting is highly likely by all women regardless of their disability status
 - Accuracy is unclear: women more accurate about whether they received screening than when they received screening
 - Accuracy of reporting by women with developmental disabilities has not been studied
- Obtained screening data from medical practices
 - Extraction forms: dates of Pap test, mammography, clinical breast exam, physical exam, insurance type
 - 91% response rate from 253 medical practices
 - Item non-response 6-9% for each procedure in last year analyzed

Percent of women receiving screening procedures, 2006-10



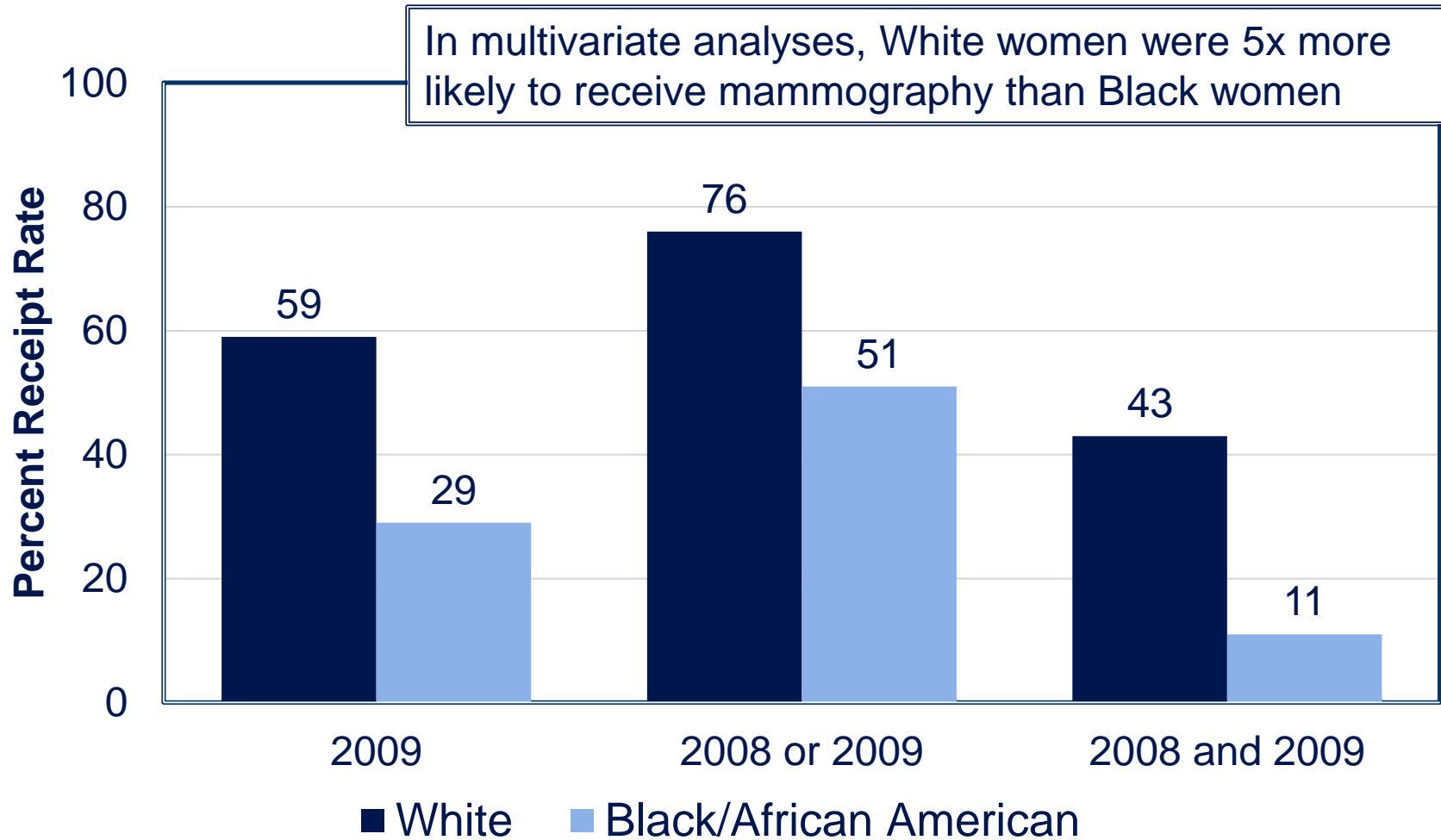
Mammography receipt among NC women ≥ 40 in 2009 or 2010



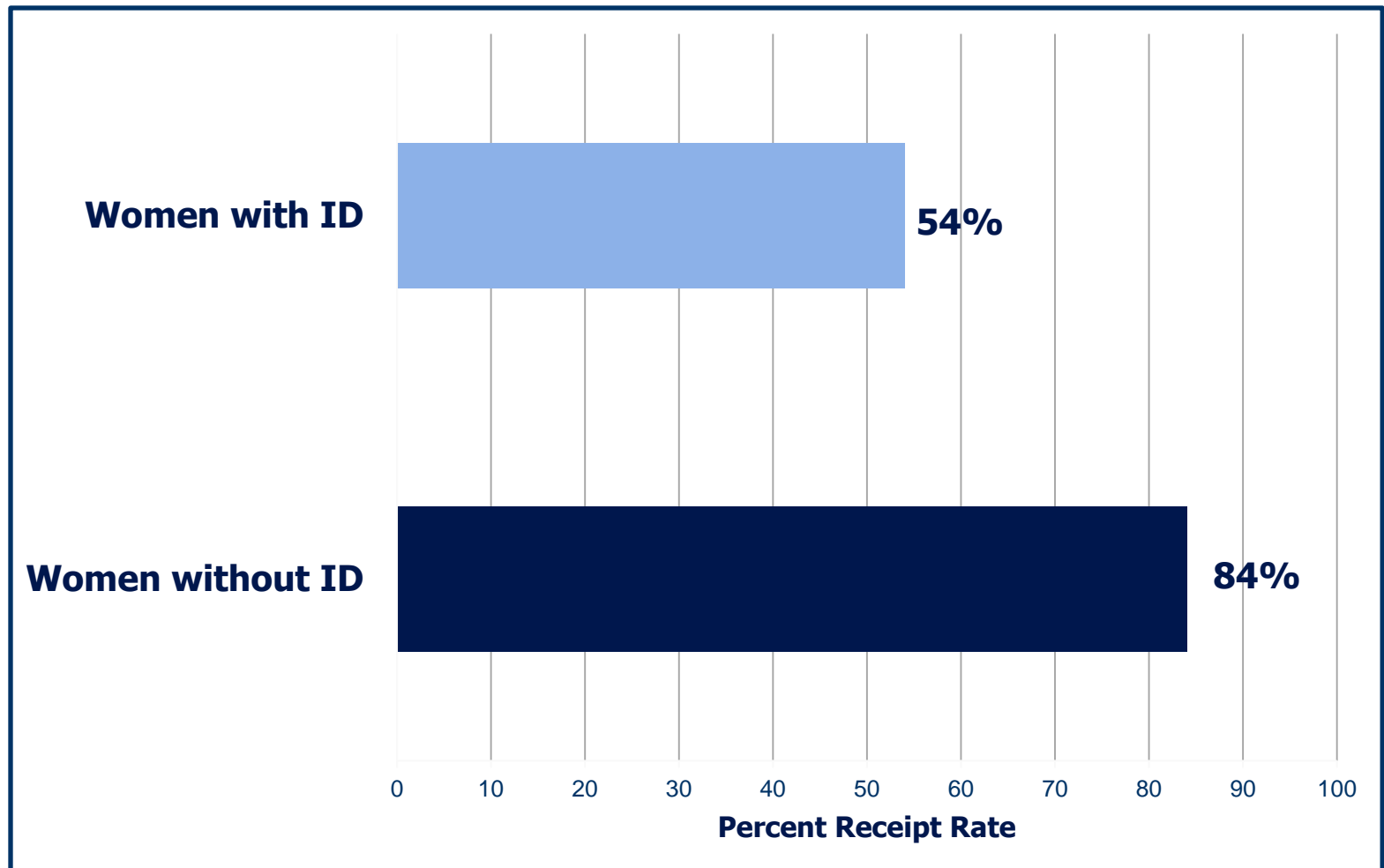
* North Carolina data from 2010 BRFSS

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Unadjusted mammography rates for Black & White women ages ≥ 40



Pap test receipt among NC women ≥ 18 in 2008, 2009, or 2010



* North Carolina data from 2010 BRFSS

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Goal: Identify determinants of Cervical Cancer Screening

Women were more likely to receive cervical cancer screening if they:

- Lived in a residential facility (as opposed to at home with family caregiver)
- Lived in a rural area
- Received care from an OB/GYN

Parish et al, forthcoming , *Public Health Reports*



Goal: Test *Women Be Healthy*

- Randomized control trial with wait-list controls
- 21 sites across North Carolina
 - Community rehab programs
 - Community colleges
 - Other disability service provider organizations
- Pre-test, post-test interview design
 - Computer-assisted, in-person interviews
- Randomized sample at each site
- Curriculum taught by on-site instructors (not research team members)
- Post-test interviews mean of 13 days after intervention

Knowledge at baseline and post-test (% correct)

Indicator	Control		Experimental		Odds Ratio
	Baseline	Post-test	Baseline	Post-test	
Define cancer	39	42	32	39	NS
Define mammogram	45	48	41	55	2.33**
Mammogram frequency	22	21	15	29	3.09**
Who should do breast exam	90	89	90	91	NS
What should you do if find lump	71	81	70	72	NS
Define Pap test	38	52	40	51	NS
Frequency of Pap test	19	29	18	37	NS
Pap instrument identification	59	70	59	70	NS
Ways to reduce anxiety	41	48	43	58	NS
9-item composite (mean)	4.3	4.8	4.1	5.0	.38**

No statistically significant group differences at baseline; Odds Ratio represents significant regressions, controlling baseline knowledge; reference group is control group; red indicates significant knowledge gains within group





Implications

- Women with developmental disabilities have low rates of cervical and breast cancer screening
- Women with developmental disabilities who live in the community have limited knowledge about cervical and breast cancer screening
- A targeted intervention, geared to learners with low literacy, can improve the knowledge about cervical and breast cancer screening of women with developmental disabilities
- Modest knowledge gains in breast cancer but not cervical cancer indicate greater duration of content related to cervical cancer is necessary
- Clear need for targeted intervention with women, caregivers, health care providers

Anecdotes & Conclusion

- Some women with ID were raped, sometimes by multiple perpetrators
- Some women had children (13% of the sample), sometimes with multiple partners
- Some women had HIV or HPV
- Many women were sexually active and/or on birth control
- Some medical providers stated that the women did not need Pap tests because of their ID
- Two physicians wrote on medical record forms “not needed because mentally retarded” *[sic]*
- *Women with ID who live in the community are at risk for developing HPV and cervical cancer and should receive Pap tests according to clinical guidelines*

Thank you!

- Participants, Advisory Board, community partner sites, instructors
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For more info:

<http://lurie.brandeis.edu/women/index.html>